



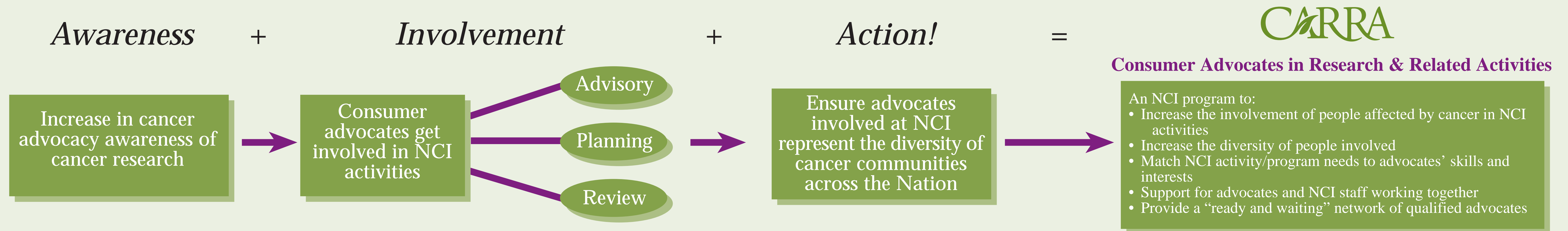
# Cancer Advocacy: From Awareness to Involvement

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**CARRA**  
Consumer Advocates  
in Research and Related Activities  
CARRA advocates make a  
difference at NCI

## Introduction

Over the past decade, consumer advocates have become aware of the importance of cancer research. Awareness led to involvement at the National Cancer Institute (NCI), with advocates serving on advisory, planning and review committees to represent the priorities of their constituencies. NCI sought to ensure that advocates involved in its programs represent the diversity of the cancer community.



## Program Goals:

- Ensure opportunities for consumer advocates to work with NCI
- Establish research priorities
- Design and implement cancer programs
- Foster an organizational atmosphere that values the contributions and perspectives of consumer advocates

## Guiding Principles:

- Involve NCI staff & consumer advocates in program development
- Reflect all participants' needs
- Ensure that activities and roles are clearly defined
- Ensure participants are educated about roles
- Reflect NCI's stature as a national-level agency accountable to the public
- Be fair, open and impartial
- Ensure diversity
- Routinely evaluate and modify procedures
- Foster understanding and value for consumer advocates' contributions

## Components of CARRA

- Program planning/development
- Recruitment
- Application
- Screening
- Selection
- Support/Consultation
  - Define roles & expectations
- Orientation
  - Advocates and staff
- Promotion
- Evaluation/Feedback

## Eligibility Criteria

- Cancer survivor, or
- First-degree family member or life partner, or
- Individual with more than 3 years of substantial, demonstrated involvement in cancer-related activities

### Who have the

- Ability to represent the perspective of a group;
- Interest in extending their personal knowledge about cancer and cancer issues; and
- Ability to speak, read, write, and understand English

## Selection Criteria

CARRA members must also have:

- Membership in a cancer-related group or organization;
- Ability to think and understand cancer issues beyond one's own cancer experience;
- Leadership qualities;
- Commitment to an organization beyond the requirements of employment;
- Interest in learning about cancer, familiarity with cancer and science-related issues, or formal training in these areas;
- Writing skills and ability to make oral presentations; and
- Ability to work as both a team player and a self-starter.

## Balance and Diversity

- Cancer type
  - 24 major and rare cancers
- Ethnicity/Race
  - all major ethnic and racial groups
  - approximately 30% minority
- Rural location
- Geographic region
  - 38 states and 2 U.S. territories
- Pediatric Cancers
- Gender
  - 35% men

## Outcome

- CARRA launched in September 2001
- 218 CARRA members

## Impact

CARRA involvement in science and communication activities, such as;

- Progress Review Groups (PRG)
- Peer Review
- Development of patient materials
- Web site development

"I was invited to be the patient representative on an NCI peer review panel for a proposed clinical trial. The other members of the panel were well respected scientists who focused with diligence and purpose on the scientific merit of the clinical trial. I, by raising issues related only to the patients, sharpened that focus. As one scientist said, 'You remind us why we are here.'"

NCI CARRA member

"CARRA members make sure that the consumer's perspective is taken into account when NCI makes recommendations about the funding of cancer research."

NCI Scientific Review Administrator

<http://la.cancer.gov/carra>